A photograph of two women laughing joyfully outdoors. The woman on the left has blonde hair and is wearing a pink top. The woman on the right has brown hair and is wearing a blue sleeveless top. They are both smiling broadly, showing their teeth. The background is a blurred green, suggesting a park or garden setting. A green rectangular box is visible on the left side of the image.

# THE 2021 Aphasia Caregiver Report

In early 2020, Lingraphica released its first Aphasia Caregiver Report, which provided a never-before-seen look at the individuals who care for someone with aphasia. The findings gave a voice and perspective to the mental, emotional, and physical demands that caregivers experience. It revealed how their relationships with others change, as well as the biggest challenges that they face.

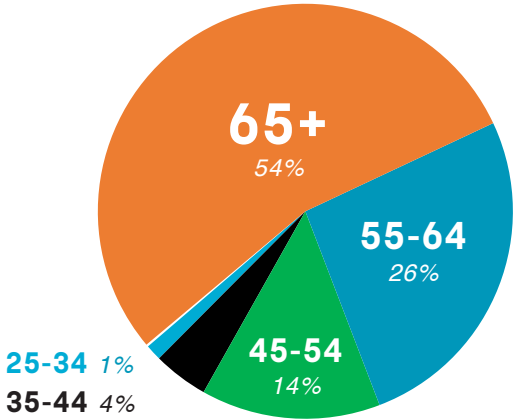
**Caregiving is important work, and our initial report made it clear just how much work it truly is.**

At the end of 2020, Lingraphica once again surveyed caregivers to learn more about their lives and the evolution of caregiving. The survey elicited responses from 558 caregivers of people with aphasia. The findings outlined in this report provide an update on the state of today's caregivers. And finally, we also highlight a key resource that has proven to be beneficial for those with aphasia and caregivers alike.

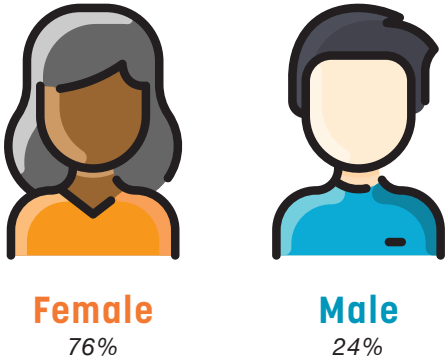
# KEY DEMOGRAPHICS

Below is basic demographic information about the 538 caregivers of people with aphasia who responded to the survey. There was minimal demographic variance between the 2020 and 2021 responders.

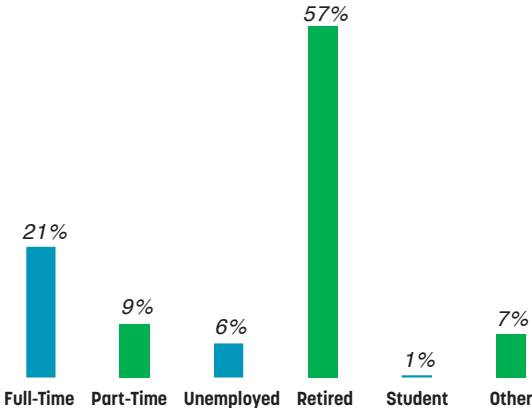
## What is your age?



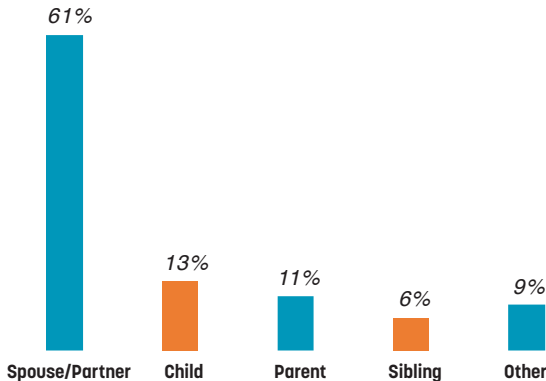
## What is your gender?



## What is your work situation?



## What is your relation to the person with aphasia?



Full-time and part-time work situations declined slightly year-over-year, while the number of unemployed and retired caregivers increased slightly. Though there's not enough data to yet call it a trend, it is a space worth paying attention to. Possible causes include factors like an aging population or a stressed economy, but the numbers presented later in this report make it clear:

**caregiving is hard work in itself.**

# The Consistent Numbers

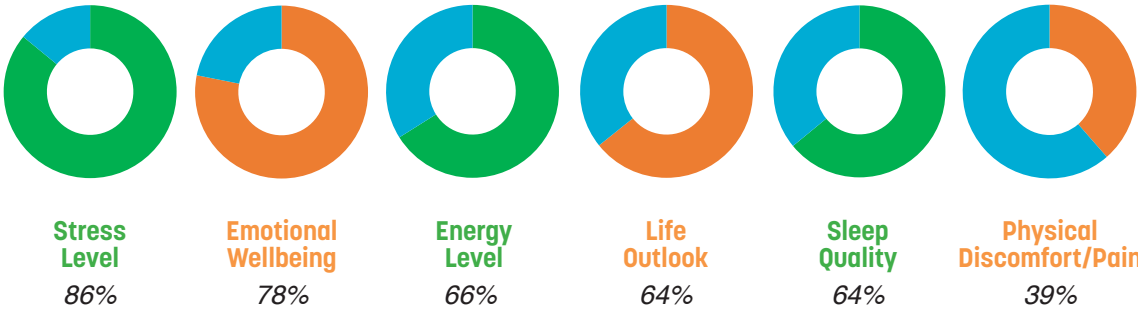
This follow-up survey further validated our original findings in [the first report](#), as there was minimal discrepancy between the two. Below is a closer look at some of the key findings.



## The Mental, Emotional, and Physical Impact of Aphasia on Caregivers

Once again, stress and emotional well-being have worsened more than other traits as a result of becoming a caregiver. Good days and bad days are to be expected, so trying to find time for mindfulness and stress management will be important.

### Percent who report worsening...

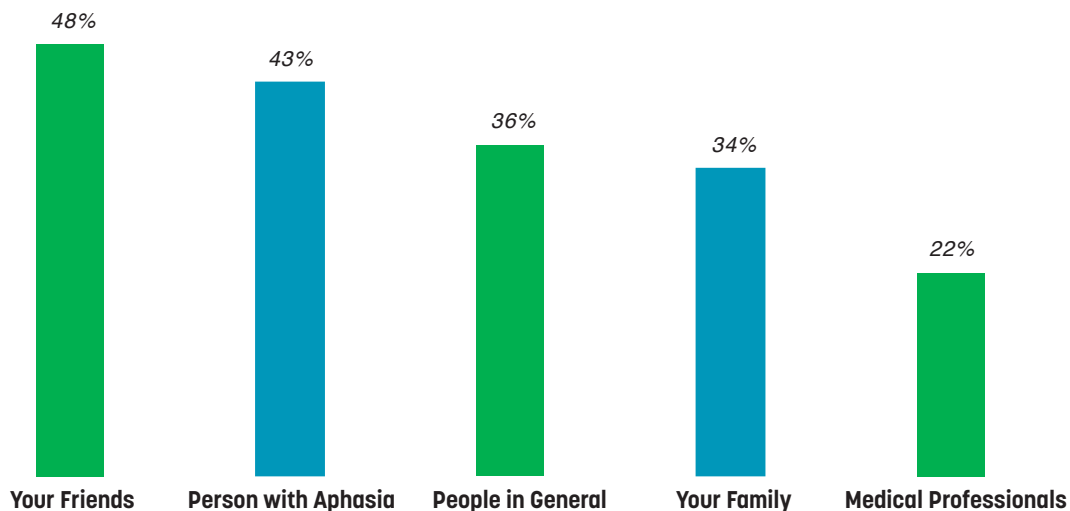




## Caregivers Experience Worsening Relationships

Nearly half of caregivers surveyed report that their relationships with friends have worsened, followed closely by their relationship with the person with aphasia. Caregiver support groups can be a great way to build new relationships while learning how to maintain existing ones.

### Percent who report these relationships worsening since the person acquired aphasia:



Since last year's report, there has been a small decrease in the number of caregivers reporting worsening relationships with friends, family, and the person with aphasia. Though the variance isn't necessarily statistically significant, it's another place to watch. The timing of the 2020 report coincided with COVID-19, so perhaps these more recent findings point to increased comfort with virtual relationships, albeit slight.

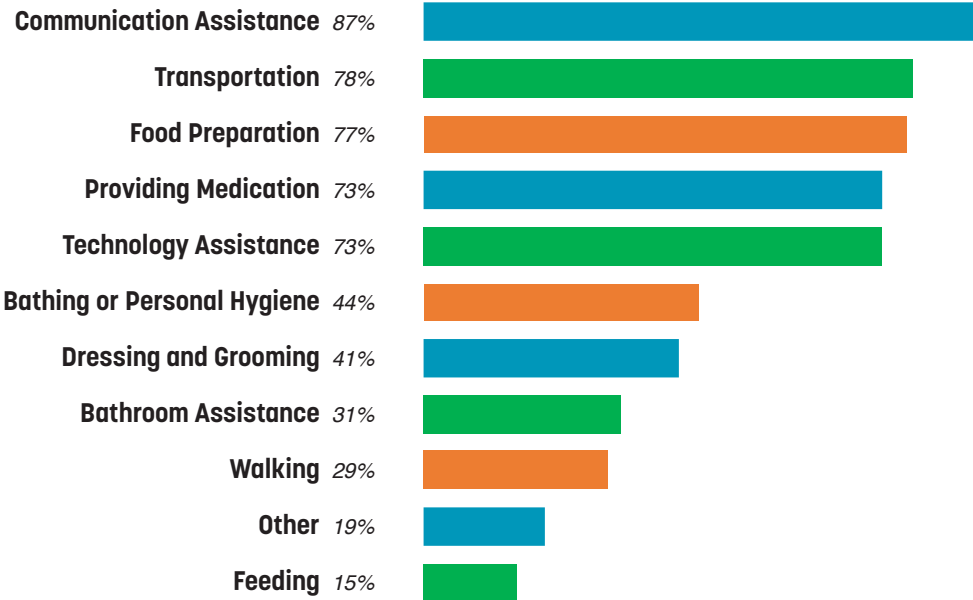




# Most Common Activities Aphasia Caregivers Help With

It's not surprising to see communication assistance top this chart. Caregiver respondents report that 53% of the time their loved one did not have a communication aid.

## I help the person with aphasia with the following:



5 HOURS



More than 56% of caregivers spend at least 5 hours a day providing care. Roughly 3 in 10 spend 10+ hours a day with care-related tasks.

### Things that take less than 5 hours:



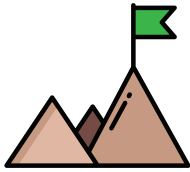
Driving from the Empire State Building to the White House



Flying from Portland, OR, to Mexico City, Mexico



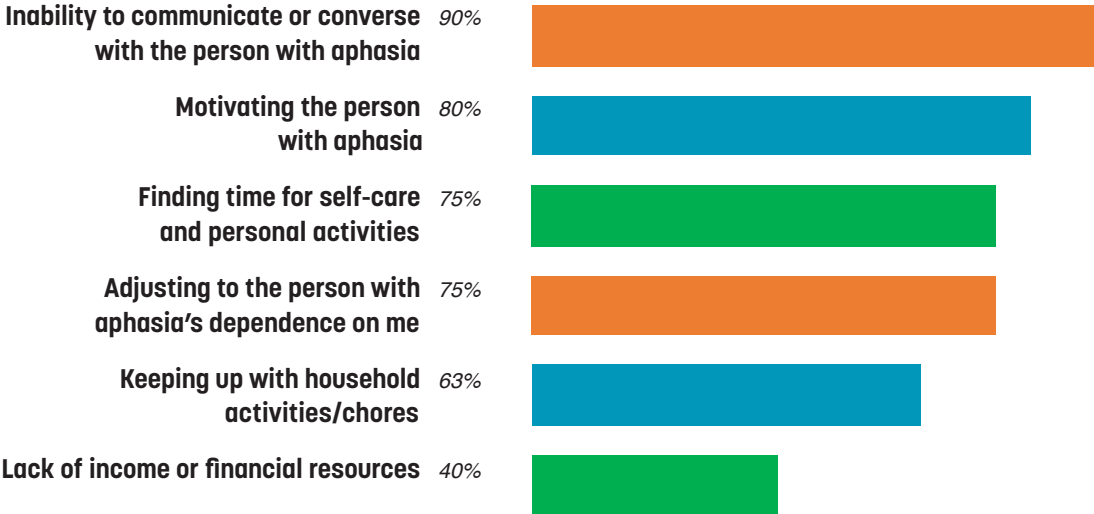
Watching the movies Home Alone 1 and 2



# The Biggest Challenges Caregivers Face

While communication remains the number one activity caregivers devote time to, it's also the number one challenge they face. Not being able to communicate with the person with aphasia is persistent in 9 out of 10 caregiving relationships. There is a clear need for support in these relationships.

## The biggest challenges I face as a caregiver:

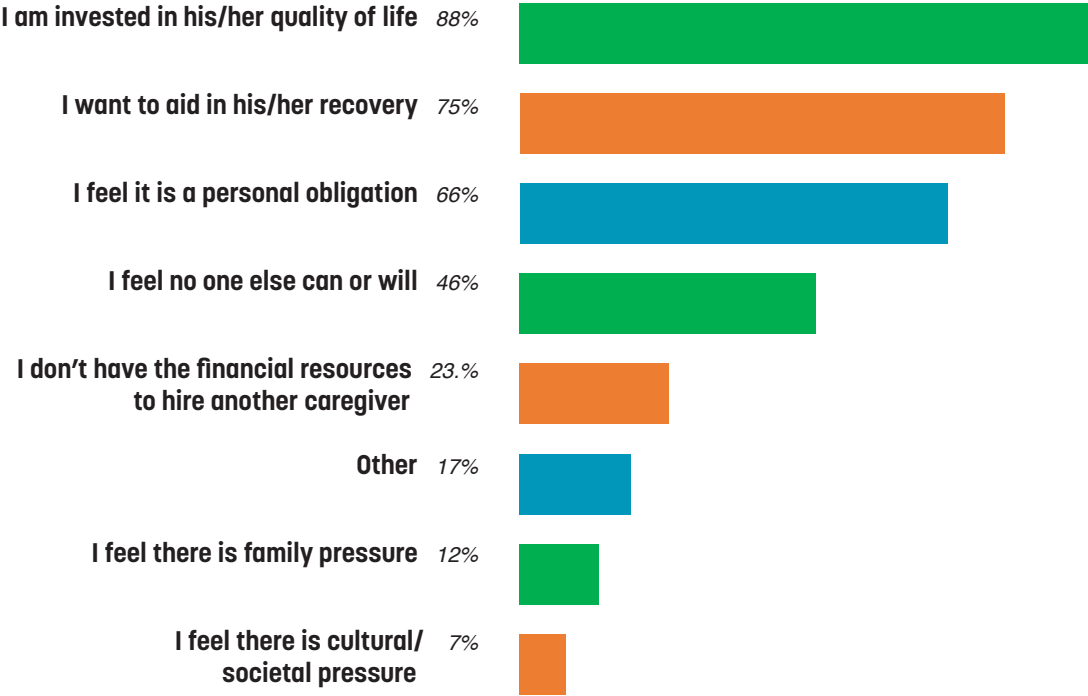




## What Motivates Caregivers to Do What They Do?

Despite the challenges and roadblocks laid out in the prior findings, caregivers are motivated by what they do best: care.

### I take care of the person because:





## Caregivers Need Care, Too

The most recent findings from our survey reveal a number of truths. The first truth is that there are unique complexities in each and every caregiving experience. There is no universal experience. The second truth is that caregivers, more often than not, face life-altering challenges with little support.

Virtual Connections is Lingraphica's online aphasia support community for people with aphasia and for their caregivers. Connect with other caregivers from across the world. Live online meetups facilitated by speech-language pathologists and other aphasia experts are available 7 days a week, completely free.

### Classes include:



**Caregiver  
Open Chat**



**Think Positive!  
Mindfulness Strategies**



**Caregivers:  
Rebuilding Your Identity**

**...and many more!**

**Sign Up for Virtual  
Connections Today!**

## About Lingraphica

Lingraphica is dedicated to helping people with speech and language impairments improve their communication and quality of life through devices, applications and resources developed by speech-language pathologists and leading researchers.

Learn more about the benefits of AAC devices at [lingraphica.com/aac-devices](https://lingraphica.com/aac-devices)

To learn more about us, visit [lingraphica.com/about-us](https://lingraphica.com/about-us)

